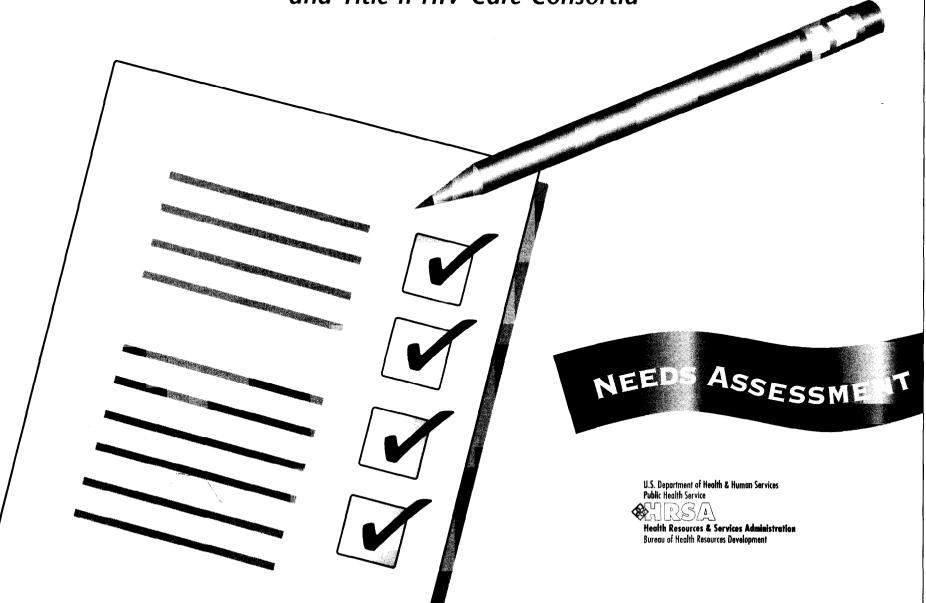
SELF-ASSESSMENT MODULE

for Ryan White CARE Act Title I HIV Health Services Planning Councils and Title II HIV Care Consortia



ACKNOWLEDGEMENTS

Authors

Patricia Fairchild, John Snow, Inc. Matthew McClain, consultant

Editor

Frances Marshman, John Snow, Inc.

Pilot Test Sites

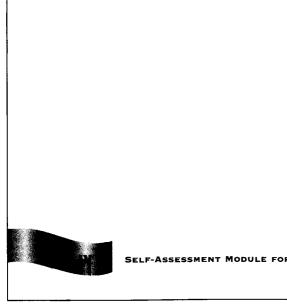
Piedmont HIV Care Consortium, Durham, North Carolina St. Louis Planning Council, St. Louis, Missouri

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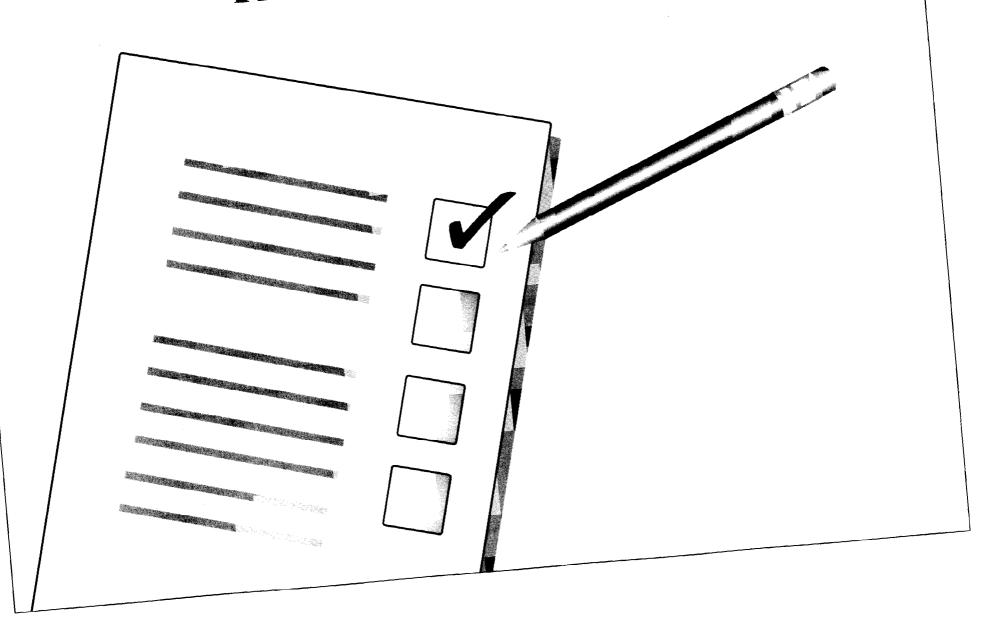
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INTRODUCTION



THE SELF-ASSESSMENT MODULE SERIES

The Division of HIV Services (DHS) and the Office of Science and Epidemiology (OSE) at the Health Resources and Services Administration (HRSA) have developed a series of tools to help HIV planning councils and consortia assess their effectiveness in critical areas of responsibility defined by the Ryan White CARE Act. The areas covered in the series are: Comprehensive HIV Services Planning, Continuum of Care, Developing and Pursuing the Mission, Needs Assessment, Priority Setting and Resource Allocation, and Representation and Diversity.

Each area is covered in a separate module. At the same time, information is complementary across the modules and cross-referenced when appropriate. The modules can be used independently of each other or as a full series.

The tools have been designed to facilitate self-assessment by planning councils and consortia. Use of any and all modules in the series is completely voluntary. Councils and consortia are free to determine which area(s) they want to assess, when to conduct the self-assessment, how extensive the scope of the assessment will be, and with whom they will share results.

DHS staff and the Technical Assistance Contractor are available to introduce the modules or to respond to any concerns raised through the self-assessment process. Please contact your DHS project officer if you have any questions about the self-assessment modules or would like assistance.

PURPOSE OF THE NEEDS ASSESSMENT MODULE

Assessing the health and social service needs of people living with HIV disease and AIDS (PLWH) is an essential prerequisite to developing a responsive service delivery system. The CARE Act recognizes the critical role of needs assessment in assuring a comprehensive array of cost-effective services. It also requires Title I Planning Councils and Title II Consortia to assess service needs. Planning councils and consortia are expected to participate in the development of a statewide coordinated statement of need led by the Title II grantee. This module is designed to help planning councils and consortia assess the effectiveness of their needs assessment process and outcomes in three primary areas:

- First, the module assesses the completeness of the components of a needs assessment.
- Second, it evaluates the process used to conduct a needs assessment.
- Third, it assesses the outcomes of the needs assessment, and how they are used in planning and priority setting.

In addition, councils and consortia will gain knowledge about specific components of a needs assessment. For example, the module will provide insight into the methods used to collect data, as well as feedback on the adequacy of the needs assessment's survey techniques, and methods of analyzing the data collected. This knowledge can be used to assess the adequacy of past activities and to help refine or expand future needs assessments.

WHAT IS NEEDS ASSESSMENT?

The purpose of conducting needs assessments is to define and describe service needs and gaps in services for people with HIV disease in order to plan, establish priorities, and allocate resources in local communities. While one objective is to assure that Ryan White funds are targeted where they are most needed, assessments also draw a comprehensive picture of an area's needs, so that all resources can be used most effectively.

Within this broad purpose, there are many variations in approaches to needs assessment. Factors such as the size of the geographic area being assessed, extent of the epidemic, diversity of populations affected, resources available to conduct the assessment, and availability of prior needs assessments influence the type and scope of needs assessment activities. To provide a context for the self-assessment, descriptions are offered of the various definitions of need, the major components of a comprehensive needs assessment, and approaches used in measuring need.

DEFINITIONS OF NEED

Needs assessments may focus on one or more types of need.

- Objective need refers to the full range of needs a person has. It is the "ideal" measurement of need based on pre-established objective standards. For example, every adult's objective need is one preventive dental visit per year. Often people aren't aware of their objective needs, and in many cases professionals can't agree on objective standards of need.
- Perceived need refers to needs that are felt and acknowledged by consumers, providers, and/or others (depending on who is asked). For example, an adult may perceive a need for preventive dental services once every three years or twice a year, irrespective of the objectively established standard.
- Demand refers to needs that are acted on, i.e., services which consumers try to obtain. This is also referred to as expressed need. For example, an adult may perceive a need for preventive dental services twice a year but because of other priorities may seek the service only once a year. Measuring demand for services is not dependent on a person actually receiving a service.

- Fulfilled need refers to a need that is addressed through
 the provision of services. Utilization of services is often a
 measure of fulfilled need. For example, an adult may seek
 preventive dental services once a year but receive services
 only once every three years because long waiting lists
 or other barriers reduce access. Occasionally, utilization
 surpasses absolute need as, for example, when a healthy
 adult receives several preventive dental services in a year.
- Unmet need refers to the difference between objective need and fulfilled need, or, in the absence of standards for objective need, the difference between expressed need (demand) and fulfilled need. For example, an adult who is unable to receive preventive dental services on an annual basis (for whatever reason) has an unmet need.

A needs assessment may address one or all of these types of needs depending on the purpose of the assessment, what previous assessments or data are available, and the resources available. To understand how to improve services, it is most productive to assess multiple types of need simultaneously. For example, looking at the difference between objective need and perceived need points to areas where consumer and/or provider education might influence care-seeking behavior. Including a measure of demand can help identify which needs are priorities for consumers. Adding information about fulfilled need can distinguish services easier to obtain from those more difficult.

COMPONENTS OF A NEEDS ASSESSMENT

There are many specific pieces that make up a comprehensive assessment of HIV service needs. The major ones are:

- An epidemiogical profile that describes the current status of the epidemic in the service area, specifically the prevalence of HIV and AIDS among defined sub-populations. The profile should also describe trends in the epidemic since its outset with a focus on trends in the last two years and projections of expected trends for the next three to five years.
- An assessment of service needs among the affected populations that explores the perspectives of PLWH, providers, and community representatives about service needs. The assessment may address some or all of the different types of need described above. A careful assessment of barriers to PLWH receiving services is an important aspect of this component. The focus should be on soliciting information from PLWH themselves, both those in and out of service. Providers can also contribute to an understanding of PLWH needs, and their perspectives may be included in this aspect of needs assessment. Provider and client priorities may differ; however, the focus must stay on the needs of the PLWH.
- A resource inventory that describes organizations and individuals providing services across the full spectrum of HIV service needs accessible to PLWH in the service area. The goal of the resource inventory is to develop a comprehensive picture of services, regardless of funding source.

- A profile of provider capacity and capability that shows the extent to which services identified in the resource inventory are accessible, available, and appropriate for PLWH. Estimates of capacity describe how much of which services a provider can deliver. Assessments of capability describe the degree to which a provider is actually accessible and has the expertise needed to deliver services. Some needs assessments will also explore acceptability of services; however, assessment of client satisfaction is a complex effort that should be undertaken thoroughly in the planning council or consortium's quality improvement process.
- An assessment of gaps in services that brings together all of the quantitative and qualitative data on service needs, resources, and barriers to help set priorities and allocate resources. This is not a precise process. Even the most comprehensive and rigorous needs assessment will have missing and/or conflicting information. It is the responsibility of the planning council or consortium to apply their best effort, wisdom, and judgment in considering all of the information available to them in defining gaps and setting service priorities.

The approach a planning council or consortium takes in completing the components of a needs assessment can vary. Some may decide to undertake a comprehensive needs assessment, consisting of all the components, at one time and repeat this comprehensive process at periodic intervals (i.e., every three to five years). Others may begin with a less comprehensive approach designed to provide critical information on service gaps quickly and then build a comprehensive assessment over time by conducting the components sequentially. For example, in its first year of operation, a new planning council or consortium may assemble state surveillance data and conduct interviews and focus groups with key PLWH and provider groups to discern high priority needs, and then design and conduct surveys of PLWH and providers in subsequent years.

Early in its operational life, though not necessarily at one time, a planning council or consortium should undertake all the components of a comprehensive needs assessment to provide a solid baseline for planning. From that base, specific components can be updated and augmented, according to available resources and the need for new information for effective planning and priority setting. Approximately every three to five years, a comprehensive reassessment of all components should be considered. Each planning council and consortium must determine which components of the needs assessment should be repeated at which intervals.



MEASURING NEED

Needs assessments are conducted using a variety of methods and types of data. Typically, a needs assessment includes analysis of quantitative and qualitative data drawn from both primary and secondary data sources. These terms mean the following in this module:

- Quantitative data are numbers that can be statistically analyzed and are used to describe what, who, when, how many, or how much in relation to a question or issue.
- Qualitative data are descriptive and usually presented in narrative form. Qualitative data can help illuminate what is happening, as well as describe how, and/or why something is occurring.
- Primary data are collected, compiled, and analyzed for the first time as part of the needs assessment process.
 Surveys, interviews, and focus groups are the main ways primary data are collected in needs assessments.
- Secondary data are existing data bases or reports
 prepared from previous studies or data collection efforts.
 AIDS surveillance data, hospital discharge data, vital
 statistics, sero-prevalence studies, Medicaid or insurance
 claims data, and needs assessments conducted by other
 groups are secondary data sources.

Most needs assessments will use quantitative and qualitative data from primary and secondary sources to provide the most complete picture of needs.

CONDUCTING THE SELF-ASSESSMENT

This section discusses how to conduct the self-assessment. It provides tips to make the self-assessment process efficient, productive, and positive. While the recommendations are based on experience and pilot tests of the modules, each planning council and consortium should adapt these processes to fit local constraints and issues. The discussion covers the following questions.

- Who should use this module?
- Who conducts the self-assessment?
- What activities should be part of the self-assessment?
- How much time and money are required?

WHO SHOULD USE THIS MODULE?

This self-assessment module is designed primarily to be completed by planning councils and consortia that have completed at least some components of a needs assessment. In other words, the module is intended for councils and consortia interested in examining needs assessment activities that have already occurred. However, the module can also be used as a development tool to design and plan future needs assessments. The action plan sections of the module are designed to apply self-assessment results to strengthen future needs assessments. For councils and consortia that have not yet conducted a needs assessment, the questions in the module can serve as a checklist for items to include in the process.



To keep these interviews focused, remember, the goals are to gain understanding about how well the assessment was conducted and to identify areas for improvement in future needs assessments, not to repeat the needs assessment itself. It is advisable to plan which questions in the module you will discuss with each person being interviewed. For example, you may want to discuss methodology with a research consultant and the inclusiveness of the needs assessment process with affected populations. This task will also require the involvement of more than one person to be completed in a timely way.

3. Answer and score the questions. After collecting relevant information and conducting key interviews, the workgroup should convene to discuss the questions in the module. Depending on the number of questions being addressed, the discussion could take four to six hours. The discussion may occur in a single meeting, in a series of meetings, or by telephone conference calls. The questions have been subdivided into sections to facilitate a segmented discussion.

Many questions will require significant discussion and coming to consensus. It is important to choose an individual who can focus and facilitate discussion.

There are two important parts to answering the questions. First, and most important, is a qualitative discussion of the question, what the council or consortium did well, and what it could do better. Second is assignment of a score when scoring is indicated. Numerical scoring is provided on several questions to help the council or consortium identify areas of strength and weakness. The scores can also provide a baseline for future self-assessments.

A question-by-question overview and discussion of scoring is provided at the end of each section. The overview elaborates on each question and how to interpret your score and answers. It may be helpful to refer to this overview while answering the questions.

The module contains four types of questions:

- a. Questions that rank responses from 0 to 3, with 0 being the lowest score and 3 being the highest. Each planning council and consortium completing the module determines where to rank itself along this continuum.
- b. Questions with a yes or no response. When the desired direction of response is known, these questions are also scored with "no" scoring 0 and "yes" scoring 3. For some yes/no questions where either answer may be equally good, depending on circumstances, no score is given.
- c. Multi-part questions in which the sub-parts are not scored, but a summary question asks for an overall assessment scored from 0 to 3.
- d. Open-ended questions that are not scored. These questions enable planning councils and consortia to highlight aspects of complex questions they feel are particular strengths or weaknesses.



WHAT ACTIVITIES SHOULD BE PART OF THE SELF-ASSESSMENT?

There are five major activities that must occur to complete the self-assessment:

- 1. Review and adapt the module to the local environment.
- 2. Collect information and documents needed to answer the questions in the module.
- 3. Answer and score the questions in the module.
- 4. Develop an action plan to guide future activities.
- 5. Apply results of the self-assessment. Tips are offered for each of these activities.
- 1. Review and adapt module. After the decision is made to proceed with the self-assessment, the first step is to review the module and adapt it as necessary. For example, questions that are irrelevant should be eliminated, and lists of stakeholders should be augmented or reduced as appropriate. Careful review of all the module's sections at the outset will facilitate its implementation and minimize frustration among workgroup members.

The module should be distributed to all members of the self-assessment workgroup approximately one week before the first workgroup meeting. This meeting, in person if possible, should be used to determine the specific scope and content of the self-assessment to be implemented, clarify the purpose of the self-assessment, define the process and time line by which the self-assessment will be conducted, assign roles and responsibilities of workgroup members, and clarify specific questions for all members. If a chair-

person has not been appointed, one should be elected at this meeting.

2. Collect information and documents, conduct interviews. Once the workgroup has agreed on the scope of the self-assessment, members should proceed with collecting and reviewing related documents, instruments, and reports. Interviews with key people involved in the needs assessment should also be scheduled.

Documents could include the final needs assessment report; tools used to conduct the needs assessment like survey instruments, interview protocols, and focus group guides (each may be in various languages); minutes and attendance logs from meetings of committees or advisory boards that participated in the needs assessment, as well as council and consortium meetings where the needs assessment was discussed; working papers and reports used in preparing the final needs assessment reports; and Request for Proposals if all or part of the needs assessment was conducted by consultants, as well as consultant reports. This task will require more than one person and should include at least one person with expertise in needs assessment methodology.

Interviews could be conducted with members of the council or consortium committee who oversaw the needs assessment; members of any advisory group formed to oversee the process; council or consortium staff who worked on the needs assessment; consultants who worked on the needs assessment; people at the grantee, council, or consortium level who used the needs assessment for planning or priority setting; and people representing affected populations or services covered in the needs assessment.

To keep these interviews focused, remember, the goals are to gain understanding about how well the assessment was conducted and to identify areas for improvement in future needs assessments, not to repeat the needs assessment itself. It is advisable to plan which questions in the module you will discuss with each person being interviewed. For example, you may want to discuss methodology with a research consultant and the inclusiveness of the needs assessment process with affected populations. This task will also require the involvement of more than one person to be completed in a timely way.

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The points in each section are added up then divided by the number of scored questions in the section. By dividing the total points by the number of scored questions, you will have a single score of 0 to 3 for each section. That score can be compared to the score in other sections. Combined with a qualitative assessment of strengths and weaknesses in each section, the scores can be helpful in highlighting areas where a planning council or consortium has done very well (high scores, e.g., 2 to 3), as well as areas in which changes or enhancements should be considered (low scores, e.g., 0 to 1).

Assigning scores is not the ultimate goal of the self-assessment. It is much more important that the group engage in substantive discussion of the questions. If you get stuck on scoring, move on. All scores are confidential and are not compared across planning councils and consortia or shared with DHS.

4. Develop action plans. Each section of questions concludes with the development of an action plan for that section. The self-assessment will be most successful if it improves future needs assessment efforts by keeping what works well, modifying what doesn't, and adding important aspects that are missing. The action plans are intended to lead a planning council or consortium forward. Particular attention should be paid to questions that were scored 0 to 1, because these may be problem areas. You should not, however, lose sight of areas of strength when planning future activities.

A format is provided for developing the action plan for each section, but it may be modified to meet the needs of a particular planning council or consortium. For each section you are asked to list objectives, time line, resources needed, and lead person responsible for completing the objective. Once the section-specific action plans are done, an overall plan with priorities should be developed.

5. Apply results. The results of the self-assessment, including answers to questions, scores, and action plans, belong to the planning council or consortium and to no one else. However, a planning council or consortium may decide to share part or all of its results with the grantee, with DHS, or with the community.

The overarching purpose for conducting a self-assessment is to improve the functioning of the council or consortium. In this case, the purpose is to improve needs assessment activities and, specifically, to help councils and consortia plan and implement needs assessments that meet legislative requirements and DHS guidelines and that provide reliable quantitative and qualitative information used in planning and prioritizing services. There may be other reasons for conducting the self-assessment, such as responding to local questions or concerns, but the self-assessment modules have been designed primarily to give councils and consortia tools to help them improve the quality of their operations. The action plan component of the module is intended to lead to such improvements. Viewing the module as a quality improvement tool supports the premise that results of the self-assessment are for internal use and do not need to be shared, except at the discretion of the council or consortium.

At the conclusion of the self-assessment, the planning council or consortium may want to develop a brief report summarizing the process. The report could address the charge to the workgroup or committee, workgroup membership, and processes used to complete the module (e.g., number of meetings, time lines, people interviewed, documents reviewed).

HOW MUCH TIME AND MONEY ARE REQUIRED?

The self-assessment process has been designed to be very low cost. Time is the principal investment required of those who help complete the module.

Once a planning council or consortium has decided to proceed with the self-assessment, the process should take between eight and twelve weeks, beginning with tailoring the module to the local environment and ending with an action plan and reporting of results to the council or consortium.

A prototype time line for the self-assessment follows. >

PHASE T DECIDING TO DO SELF-ASSESSMENT

- Week 1: Convene evaluation committee to consider the self-assessment process, recommendations to planning council or consortium.
- Week 2: Planning council or consortium decides to proceed with self-assessment, identifies *ad hoc* workgroup to conduct assessment, writes charge to the workgroup, decides who will get results.

PHASE II PREPARATORY WORK

- Week 3: Self-assessment module distributed to workgroup members for review, first meeting of workgroup scheduled.
- Week 4: Workgroup meets, elects chair, reviews and modifies questions, assigns responsibilities.
- Weeks 5-8: Documents reviewed, interviews conducted.

Phase III Answering Questions

- Week 9: Workgroup meets to discuss and to score questions, develops action plans for completed sections.
- Week 10: Workgroup meets to complete discussion of action plans.

PHASE IV REPORTING AND IMPLEMENTING

- Week 11: Present results to planning council or consortium, report on process and final decision.
- Weeks 12-14: Decide on overall plan and implementation, request technical assistance, if needed.

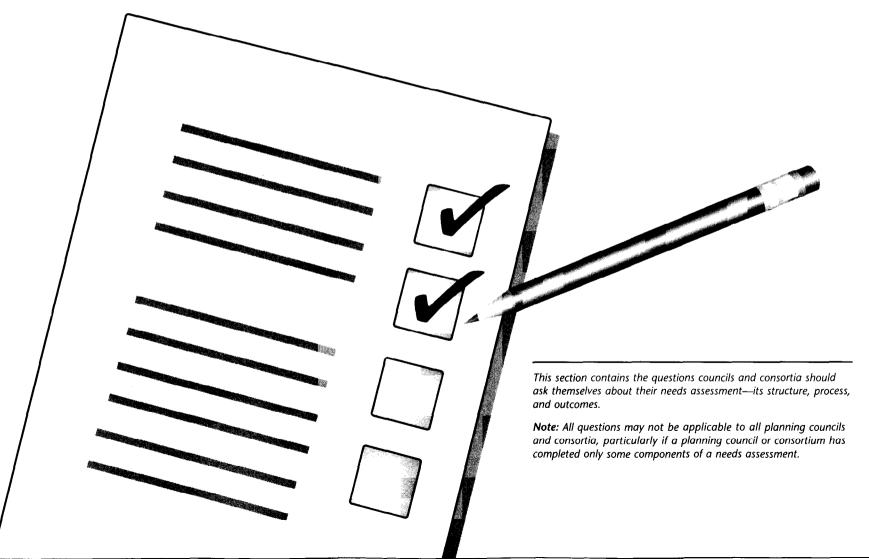


INFORMATION SOURCES

To complete the Needs Assessment module, you will need:

- statement(s) of goals and objectives for the needs assessment
- Request for Proposal or consultant contracts
- meeting minutes
- public announcements about the needs assessment
- initial needs assessment plan
- instruments used (e.g., surveys or interview protocols), and
- final needs assessment report(s).





NEEDS ASSESSMENT STRUCTURE AND PROCESS

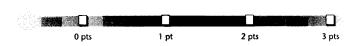
A. DESIGNING THE NEEDS ASSESSMENT Was an individual, committee, or workgroup assigned to design the needs assessment? no yes 0 pts 3 pts Was an individual, committee, or workgroup assigned to conduct the needs assessment? no yes 0 pts 3 pts To what extent were people living with HIV/AIDS involved in designing the needs assessment? significant not involved involvement 2 pts 0 pts 3 pts To what extent were people with expertise in needs assessment methodology involved in designing the needs assessment? significant not involved involvement 0 pts 3 pts

4	Based on your experience, what perspectives and expertise are important to include when designing needs assessments	?			
5	Was there a clear statement of the goals of the needs assessment prior to beginning the design process?	no statement of g	oals	w	ritten goals
		0 pts	1 pt	2 pts	3 pts
6	Did the goals, at a minimum, address legislative requirements and DHS guidance regarding needs assessment? (Refer to the discussion at the end of this section.)			a	ddressed all
	,	not addressed			quirements
		0 pts	1 pt	2 pts	3 pts
7	Were research questions or objectives clearly defined in the design of the needs assessment?	no questions or objectives define			questions or es clearly defined
		0 pts	1 pt	2 pts	3 pts

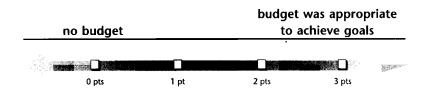
Were a time line and budget established, and were they reasonable to achieve the goals?

Time line

viable time line established and followed



Budget



To what extent did the planning council or consortium consider information conducted by other local and state agencies or organizations in designing its needs assessment?

no attempt to consider information from other organizations

no time line

information from existing organizations fully considered



A list of some organizations involved in assessing HIV-related needs follows. Not all communities will have all of these organizations in place, while some communities may have other relevant planning activities which can benefit the planning council or consortium. Also, not all organizations will have useful information. For example, information may be out-of-date, incomplete, or address issues outside the scope of the planning council or consortium assessment. The chart on the next page is designed to help answer the question above.

Question 9	Considered Information from C	Other C	Groups		
COORDINATING	GROUP	IN EXIS	STENCE?	INFORMATION	CONSIDERED?
		No	Yes	No	Yes
CDC HIV Prevention Cor	mmunity Planning Groups				
Statewide Coordinated S	Statement of Need (SCSN) working group				
Title IIIb grantees		ū			
Title IV grantees					
Planning council or cons	sortium with overlapping service areas				
AIDS Education and Train	ning Center (AETC) programs				
Special Projects of Natio	nal Significance (SPNS)				
Substance Abuse and Me	ental Health Services Administration (SAMHSA) programs				
Housing Opportunity for	People with AIDS (HOPWA) programs				
Federally-funded Migran	t, Homeless, and Community Health Centers				
Maternal and Child Heal	th programs				
TB programs					
STD programs					
State Medicaid program					
Other					
Other			J		

What methods and data sources were considered in designing, and which were used in conducting the needs assessment?

Needs assessments should use a combination of qualitative and quantitative methods. Specific methods used will depend on many factors, including the goals of the needs assessment, research questions to be addressed, and time and money available to conduct the needs assessment. This two-part question asks whether a range of methods was considered in designing the needs assessment, and whether appropriate methods were used in conducting the assessment. The following chart includes several methods and data sources often used in HIV needs assessment and is designed to help answer questions 10a-d. \rightarrow

Question 10 Considered Methods in Designing ar	nd/or Us	ed in Condu	cting a Needs	Assessme	nt
METHOD/DATA SOURCE	CONSIDERED?		USED?		
	No	Yes	No	Yes	
Review of Secondary Data					
Previous HIV-related needs assessment (e.g., CDC, AETC, IIIb—See list in question 9)				ū	
Consortia-related assessments/plans					
HIV/AIDS surveillance data					
Sero-prevalence studies					
Data related to high-risk populations (e.g., homeless, IDUs)			ū		İ
Data on co-morbidity factors (e.g., TB, STDs, adolescent pregnancy)					
Insurance and Medicaid claims data					
Hospital discharge data					
Enrollment and/or utilization data					
Analysis of provider records (e.g., waiting lists, case management referrals)					
Other					
Other					

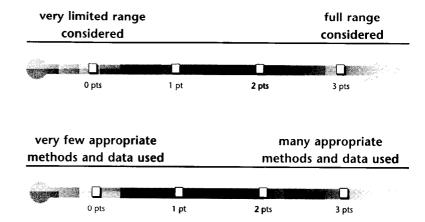
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Question 10 continued					
METHOD/DATA SOURCE	CONSID	US	USED?		
	No	Yes	No	Yes	
Surveys (mail, telephone, in-person)					
Of PLWH					
Of Providers					
Of Community Leaders					
Other					
Interviews (telephons) berron)				ESINE	S
Of PLWH					
Of Providers					
Of Community Leaders					
Of Grantee					
Other					
For succession					
Of PLWH					
Of Providers					
Of Community Leaders					
Other					
Public Forums/Hearings					
Call-In Line					
Informal Discussions					

Was a range of methods and data sources considered in designing the needs assessment?

To what extent were appropriate methods and data sources used in conducting the needs assessment?

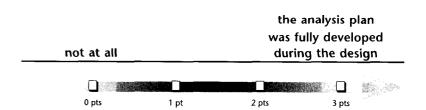


Which methods and data sources were most useful in conducting the needs assessment, and why?
Which were least useful and why?

Most	Why?
Least	Why?

10d	What methods should be considered for use in future needs assessments?					

To what extent was a plan for analyzing results developed during the design of the needs assessment?



SUMMARY: DESIGNING THE NEEDS ASSESSMENT

SCOR	RING	STRENGTHS AND WEAKNESSES
To score	e, follow these steps:	What aspects of designing the needs assessment worked well
STEP 1	Add up the points for questions 1 through 11 and put that amount in the TOTAL POINTS box.	and should be retained?
STEP 2	Add up the number of scored questions answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.	
STEP 3	Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.	What should be added or improved?
STEP 4	Record your final score in the SCORE box.*	
SCOR	TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED	
	equals	ACTION STEPS
	SCORE	Based on your responses to questions 1 through 11, list the key areas where action is needed in designing future needs assessments. Action steps may address areas of strength that



the planning council or consortium wants to retain in future

needs assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments. →

^{*}If your score equals more than 3, double-check your addition of points and counting of subquestions answered.



ACTION STEPS FOR QUESTIONS 1-11

	31 30 20 110110 1 11
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:



DESIGNING THE NEEDS ASSESSMENT: DISCUSSION OF SCORING AND QUESTIONS 1-11

Following is a discussion of **questions 1-11**. The discussion is intended to help interpret the questions and assign scores.

This section asks about who was involved in designing the needs assessment, whether the needs assessment started with clearly articulated goals, whether thought was given to the time and resources needed to carry out the needs assessment, whether the planning for the needs assessment involved organizations which could provide information for the assessment, and what methods and data sources were considered in designing the needs assessment. Questions 1a and 1b award maximum points if a person or group was assigned specific responsibility for designing and conducting the needs assessment. Generally, a committee or workgroup is preferred to an individual in order to include diverse perspectives. It is not necessary that the same person or group oversee both the design and implementation of the needs assessment, but some continuity throughout the process may help ensure efficiency. Questions 2-4 ask about who was involved in designing the needs assessment. It is advisable to include diverse perspectives at the outset. People living with HIV whose needs are being assessed, providers who will be asked to contribute information for the assessment, planning council or consortium members and funders who will use the results, and people with expertise in needs assessment methods can all make valuable contributions to designing the needs assessment.

Benchmark: Needs assessments must be as inclusive as possible. PLWH must participate in the needs assessment process. Grantees, community representatives, and service providers should also be included. Inclusion begins in the design phase.

Each community must select key people with diverse perspectives and expertise to be involved in designing the needs assessment while maintaining a reasonably sized planning group, e.g., five to ten people. Question 2 asks about involvement of PLWH in designing the needs assessment. PLWH can make important contributions to the design by helping define key services or populations that should be the focus of study, suggesting effective ways of collecting data from PLWH, and describing how the PLWH community can use the results of the needs assessment. Give yourself maximum points for question 2 if you included a diverse group of PLWH in the design of the needs assessment and incorporated their suggestions into the design. Give yourself maximum points for question 3 if you included people with expertise in needs assessment methodology in designing your needs assessment. Needs assessments often involve surveys, interviews, and focus groups to collect data, some of which involve complex methods and analyses. People with research expertise are important to ensure that the needs assessment produces the best data possible given the resources available. Use question 4 to highlight expertise and perspectives you think should be included when you are designing future needs assessments.

Having predefined goals for the needs assessment helps assure that the needs assessment results in information directly useful in planning. Give yourself maximum points on **question 5** if your planning group developed written goals for the assessment, and fewer points if goals were discussed but not written. **Question 6** specifically relates to HRSA requirements based on legislation and guidance. These are as follows:

Benchmark: Consortia must demonstrate that they have carried out an assessment of need in the geographic area to be served and have developed a plan to ensure delivery of services to meet identified needs. Planning councils are required to undertake a needs assessment process to document and quantify unmet need for specific services.

Question 7 asks whether specific research questions or objectives were defined during the design phase of the assessment. The more explicitly the questions are articulated in the design phase, the more likely the information collected will be useful. It is always inadvisable (and expensive) to collect information for information's sake. Ideally, a planning council or consortium will formulate clearly written and very specific questions during the design phase. This earns maximum points. More general objectives for the needs assessment, or questions that cover only parts of the assessment, should receive fewer points.

Question 8 gives points if a budget and time line for the assessment were developed and followed. You may give yourself maximum points even if the budget and time line were revised during the process. Similarly, if you developed budgets and time lines for specific components of the needs assessment,

score maximum points. Budgets and time lines are important to assure that desired information is collected in a cost-effective way and in line with internal or external deadlines.

Question 9 asks whether information available from several different groups was considered in designing the needs assessment. Needs assessments can be expensive and timeconsuming to conduct, and a council or consortium should strive to build their assessments on data and information that is already available. A chart is provided to help answer this question. The groups listed in the chart have often conducted needs assessments or have data that are directly relevant in the council or consortium assessment. Many communities will not have all these organizations in place, so the chart asks first whether a particular group exists in the community and next whether information from the organization was considered. Maximum points should be awarded if the council or consortium discussed and reviewed information available from groups that exist in its area. Actually using the data as part of the needs assessment is not required to earn maximum points because some information may not be relevant or useful.

Benchmark: Needs assessments should be coordinated with other related efforts, e.g., CDC HIV Prevention Community Planning Groups, other CARE Act Titles, AETCs.

Benchmark: Planning councils and consortia are expected to participate in the development of the Statewide Coordinated Statement of Need working group led by the State.

Question 10 presents an extensive list of secondary data sources and primary data collection methods that may be used in a needs assessment. No council or consortium is expected to have used all these data sources and methods, but every council or consortium should assess a range of methods carefully and select those which are best suited to their goals, research questions, and available resources. Question 10a asks whether a range of methods were considered in designing the needs assessment. Question 10b asks the extent to which appropriate methods were used in the needs assessment. Questions 10c and 10d are open-ended and highlight which methods were most useful, which were less useful, and which methods should be considered in future needs assessments. The chart provided helps highlight some methods that might be considered and used.

While specific data sources or methods may be inappropriate in a given situation, generally, needs assessments should use a combination of qualitative and quantitative methods to ensure the most complete picture of need. State surveillance data should be used in all needs assessments.

Benchmark: Planning councils and consortia should establish methods such as public meetings, focus groups, and *ad hoc* panels for obtaining input on community needs and priorities.

Benchmark: Epidemiological data should be part of the needs assessment. AIDS surveillance data and estimates of HIV disease incidence and prevalence should be used to describe trends in the epidemic since the outset and in the last two years. These trends should be forecast three to five years, as appropriate.

Benchmark: Both quantitative and qualitative data should be used in conducting the needs assessment.

Question 11 concludes the section. It asks whether an analysis plan was developed during the design of the needs assessment. The clearer you are at this stage about what data you will collect, how you will analyze the data, and how the data will achieve your research goals, the more effectively you will be able to carry out the needs assessment. Award maximum points when a detailed analysis plan was developed during the design phase.

B. CONDUCTING THE NEEDS ASSESSMENT

To what extent did key stakeholders participate in the needs assessment? (Refer to Figure 1 for a list of stakeholders.) →

Many people and organizations have a stake in the needs assessment. First and foremost are the people whose needs are being assessed, people living with HIV disease. In addition, stakeholders include individuals and organizations providing services to affected populations, activists, officials, and leaders who are concerned with the well-being of the community, members of the planning council or consortium who will apply the results of the needs assessment, and agencies which provide funding or other resources for HIV services.

The clear objective in conducting the needs assessment is to be as inclusive as possible. The needs assessment process should be inclusive in terms of who participates in the design, analysis, and application of the needs assessment. It should also be inclusive in terms of what information is collected and from whom.

The following list is intended to help planning councils and consortia think about who is included in their needs assessment, not to be inclusive or prescribe ways for organizing stakeholders.



FIGURE 1

Stakeholders in HIV/AIDS Needs Assessment

Note: The clear objective in conducting HIV needs assessments is to be as inclusive as possible. The needs assessment process should be inclusive in participation in the design, analysis, and application of the needs assessment; and whom data are collected from and about. There are many ways to divide stakeholders into groupings, e.g., demographically, geographically, stage of illness, type of service.

The list of potential stakeholders is extensive, especially when combinations of categories are considered. This list is intended to help planning councils and consortia think about who is included in their assessment, not to be exhaustive or prescribe a specific way of categorizing stakeholders. Stakeholders may be divided into five major groups: affected populations, providers, organizations, community leaders, and funders/collaborators.

AFFECTED POPULATIONS

Note: Affected populations may be categorized along numerous dimensions. Selection of categories of affected populations will depend on the epidemiology of the epidemic in the area being assessed, the goals and objectives of the needs assessment, and the availability of and/or ability to develop reliable data. Some possible ways consumers can be grouped:

- Demographics: e.g., gender, race/ethnicity, age, income
- Transmission mode: e.g., men who have sex with men, IDU, blood product, heterosexual, perinatal
- Geography: e.g., rural/urban, political subdivisions within EMA or consortium area, census tracts, or zip codes
- Stage of illness: e.g., HIV versus AIDS
- Co-morbidity factors: e.g., mental illness, substance use, pregnancy, TB, STDs
- Coexisting social factors: e.g., homeless, undocumented residency, recently released from prison, sex worker, non-English speaking
- Infected versus affected

TYPES OF INDIVIDUAL PROVIDERS

Note: Providers may also be categorized in a number of ways, by type of service, geographical location, credentials, etc. They may be included as individuals (e.g., physicians or home care nurses) and/or as organizations (e.g., hospitals or home care agencies).

- Primary care: e.g., pediatrics, internal medicine, obstetrics/ gynecology, family practice; and/or MD, DO, PA, NP
- Medical specialties: e.g., infectious disease, dermatology, oncology, ophthalmology, pulmonology, neurology, psychiatry
- Nurses
- Mental health: e.g., social workers, psychologists, nurses, psychiatrists
- Case managers (medical/RN, social model)
- · Dentists and hygienists
- Substance abuse counselors
- Supportive housing staff
- Nutritionists
- Buddies
- Pastoral counselors
- Pharmacists

TYPES OF ORGANIZATIONS

Note: These will vary by community, but types of organizations to consider are:

- Community and migrant health centers
- Group practices
- Health departments
- Hospitals
- · Home care agencies
- AIDS service organizations
- Mental health centers
- Substance abuse treatment centers
- Homeless shelters
- Prisons
- Meals on wheels and food pantries
- Hospice

COMMUNITY LEADERS AND ACTIVISTS

Note: These will vary by community, but types of people to consider are representative of:

- · religious communities
- business communities
- · women's groups
- gay/lesbian groups
- · racial/ethnic groups
- HIV activist groups
- neighborhood/community coalitions
- PLWH groups

FUNDERS/ COLLABORATORS

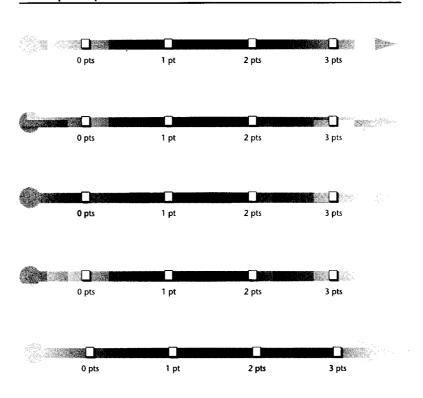
Note: These could be few or several, depending on the service area. A list of potential collaborators is included in the summary chart for Question 9. In addition, the Title I or II grantee and any other significant funders (e.g., foundations) should be included in the process.



There are many ways people may participate in the needs assessment: on committees, workgroups or advisory boards, as participants in focus groups, as key informants in interviews, as survey respondents, in public hearings, as interviewers or focus group moderators, or in analyzing results. The chart below is designed to help answer questions 12a-g.

Check if participation is satisfactory.	PLWH	COMMUNITY PROVIDERS	COUNCIL/ CONSORTIUM LEADERS	MEMBERS	FUNDERS
On committees or workgroups					ā
On advisory boards					
As participants in focus groups					
As key informants in interviews					
As survey respondents					
In public hearings					
As interviewers or focus group moderators			Ġ		
In the analysis					
In commenting on draft reports					
Other					

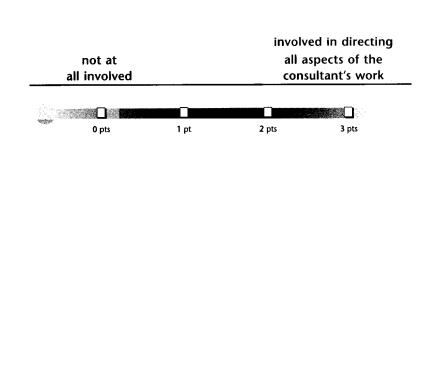
- To what extent did PLWH participate in the needs assessment?
- To what extent did HIV service providers participate in the needs assessment?
- To what extent did community leaders and activists participate in the needs assessment?
- To what extent did planning council or consortium members participate in the needs assessment?
- To what extent did funders participate in the needs assessment?



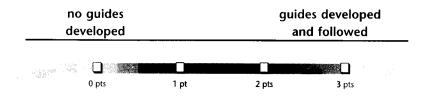
Were there any other stakeholders who made an impor- contribution to the needs assessment?
List any groups that have not participated adequately in past needs assessments but should be included in the future.
· · · · · · · · · · · · · · · · · · ·

13	For councils and consortia that contracted some or all of
IJ	the implementation of the needs assessment, how involved
	were planning council/consortium members in setting
	objectives, designing the needs assessment, and reviewing
	the consultant's work?

 	 	 <u> </u>
 	 -	
 # L	 	



For focus groups or interviews, was a discussion guide used to ensure that the desired questions were asked of each group or individual?



For focus groups or interviews, to what extent was training for facilitators/interviewers assured?

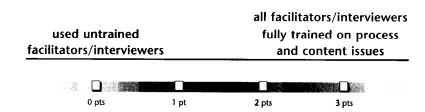


FIGURE 2 Conducting Surveys of PLWH

Questions 17-25 address the process by which surveys of PLWH were conducted. Many of these questions address issues of survey methodology and may be best answered by someone with expertise in methodology. Conducting surveys of PLWH presents particular challenges. Because the universe of people living with HIV disease is not known, it is impossible to conduct a survey based entirely on random or probability samples. Moreover, even when lists are available for some groups (e.g., those in the care of a particular provider), issues of confidentiality make standard survey implementation practices of mailed or telephone surveys with follow-up difficult to administer. Despite these constraints, however, it is important to follow as many of the principles imbedded in rigorous survey research as possible in order to achieve an accurate picture of the needs of PLWH in the area:

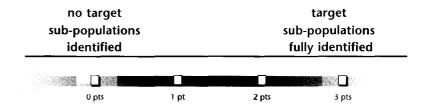
 Trying to reach all key population groups of interest, not just those most convenient to reach. Within each group it is also important to reflect the diversity present in the population in terms of geography, income, stage of illness, racial/ethnic identity, age, gender, family status, etc.;

- 2. Having a plan for approaching people to respond to the survey that is systematic and doesn't just include those most motivated to participate or those who happen to be in a certain place at a certain time;
- 3. Assuring that a large enough number of people respond to the survey(s) so that you are confident the answers reliably reflect the group and not just those of a few individuals;
- 4. Comparing the characteristics of people responding to the survey(s) to known characteristics of the HIV population in the community and weighting your analysis to adjust for differences.

Every survey will not be able to achieve all these principles. The following questions are intended to highlight key aspects of survey(s) with PLWH that will lead to the best information on which to base service decisions.

If the needs assessment did not include surveys of PLWH, please skip to question 26.

To what extent were target sub-populations identified in the survey(s) design?



Did the survey design(s) include specific strategies for collecting information from target sub-populations of people living with HIV disease, and were the strategies successful in reaching these sub-populations?

People living with HIV disease have different service needs and priorities based on many factors, including where they live, their income and insurance, their gender, and whether they have other illnesses in addition to their HIV infection (co-morbidity factors). In surveying PLWH, it is important to define key sub-populations within the service area and to design specific strategies to reach each group. The goal is to reach enough people in each group so that conclusions about that group's need can be made with confidence. The chart on the following page has been designed to help answer questions 17 and 18a-d.

Question 18

Considered specific strategies to reach target sub-populations of PLWH and success in reaching people within this population

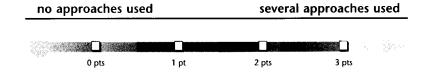
of PLWH and success in i	reaching po	eople withi	n this pop	oulation	
	CONSIDERED SPECIFIC STRATEGIES?		REACHED PEOPLE WITHIN THIS POPULATION?		
SUB-POPULATION	No	Yes	Not at all	Significant participation	
Pregnant women					
White/Anglo men who have sex with men					
Men of color who have sex with men			95a ra - C		
Injecting drug users					
Other					
Other					
Other					
To what extent were specific strategies considered to reach target sub-populations?		no specific egies considered		specific strategies ful considered for eacl target sub-populatio	
	white white	O pts	1 pt	2 pts 3 pts	
To what extent were strategies successful in reaching				-rr	
target sub-populations?		not at all successful		successful in reaching al target sub-populations	
		0 pts	1 pt	2 pts 3 pts	

18c	Were specific sub-populations targeted but not reached? What barriers were encountered in reaching these sub-populations?				
	Sub-population(s)	Barriers			:
18d	List sub-populations to be targeted in future surveys and list strategies to reach them.				-
	Sub-population(s)	Strategy(ies)			
19	To what extent were there systematic procedures for recruiting people to participate in the survey(s)?	no procedures			defined and ved procedures
		0 pts	1 pt	2 pts	3 pts
50	How successful was the project in getting people who were approached to participate in the survey(s)?	less than 25%		mo	re than 70%
	were approached to participate in the survey(3):	responded			esponded
		0 pts	1 pt	2 pts	3 pts



5.

Were different approaches used to encourage high response rates among groups being surveyed?



The following chart lists approaches that may help achieve high response rates. Not all are appropriate for every situation; there may be other approaches that are effective in increasing response rates.

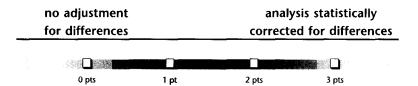
Question 21	Approaches Used to Encourage P	articipation	
			APPROACH USED?
Approach			Yes
Interviews scheduled at conv	enient times and locations		
Incentive for participation			
Translation of written instrum	ents for non-English-speaking respondents		
Opportunity to complete oral	ly for people with difficulty reading written instruments		
Follow-up reminders for non-	respondents		
Child care while participating			
Assistance with transportation	n		
Other			

21a	What approaches should be used to help achieve high response rates in future surveys? List both those that have worked well in the past and new approaches that could be helpful.	

To what extent were comparisons made between the characteristics of people responding to the survey(s) and the most currently available epidemiological data for the community?

respondent characteristics
no comparison
made
fully compared to
community data

To what extent did analyses weight the characteristics of people responding to the survey(s) to correspond to the most currently available epidemiological data for the community?

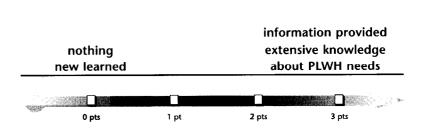


To what extent were all survey instruments, including translated instruments, pretested before implementation?

no all instruments pretested, instruments pretests of pretested translated instruments

O pts 1 pt 2 pts 3 pts

To what extent did the questions included in the survey(s) give useful information about the needs of PLWH?



SUMMARY: CONDUCTING THE NEEDS ASSESSMENT

SCORING	STRENGTHS AND WEAKNESSES		
To score, follow these steps:	What aspects of conducting the needs assessment worked v		
STEP 1 Add up the points for questions 12 through 25 and put that amount in the TOTAL POINTS box.	and should be retained?		
STEP 2 Add up the number of scored questions answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.			
STEP 3 Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.	What should be improved?		
STEP 4 Record your final score in the SCORE box.*			
TOTAL POINTS divided by TOTAL NUMBER OF SCORED			
QUESTIONS ANSWERED	ACTION STEPS		
equals SCORE	Based on your responses to questions 12 through 25, list the key areas where action is needed in conducting future needs		

key areas where action is needed in conducting future needs assessments. Action steps may address areas of strength that the planning council or consortium wants to retain in future needs assessments, aspects of the needs assessments that should

be modified, and/or additions to improve future assessments. ->

^{*}If your score equals more than 3, double-check your addition of points and counting of subquestions answered.



ACTION STEPS FOR QUESTIONS 12-25

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
· ·	·
TIME LINE:	PERSON RESPONSIBLE:



CONDUCTING THE NEEDS ASSESSMENT: DISCUSSION OF SCORING AND QUESTIONS 12-25

Following is a discussion of questions 12-25. This section addresses how the needs assessment was conducted. It looks at who was targeted in the needs assessment and how information was collected from various target groups. It also asks several specific questions about how surveys of PLWH were conducted. Some of these questions are quite technical, so you may want to include a person with expertise in survey methodology and statistics in this aspect of the self-assessment, if it applies to you.

This section starts with question 12, a multi-part question that asks about the extent to which various stakeholders participated in the needs assessment. The question recognizes that many different people have a stake in an HIV services needs assessment. Most important are the people living with HIV disease who may gain or lose access to services, depending on the results of the needs assessment. PLWH must have confidence in the needs assessment process, so that they participate actively in providing information about their needs and in using the results to set service priorities. The needs assessment process must recognize sub-populations of PLWH and target high priority groups to ensure their inclusion in the process.

Other stakeholders include organizations and individuals who provide services to PLWH and must provide information for the needs assessment and respond to results with services; activists, officials, and leaders who are concerned with the well-being of the community; members of the planning council or consortium who will use the needs assessment in services planning and resource allocation; and agencies that provide funding or other resources for HIV services. Figure 1

includes a list of possible stakeholders in an HIV needs assessment. The figure is not intended to be all-inclusive, nor is every community expected to have all these stakeholders. The figure is provided to help you think about stakeholders in your community. The clear intent in conducting needs assessments is to be as inclusive as possible. Questions 12a-g are intended to help you assess how and how well you included key stakeholders in the needs assessment. A chart, suggesting ways stakeholders might be involved in your needs assessment, is included to help answer the questions.

Questions 12a-e ask about the participation of specific groups: PLWH, service providers, community leaders and activists, planning council or consortium members, and funders. It is important to include stakeholders, particularly people living with HIV disease, in as many ways as possible, not only to ensure the relevance of information but also to encourage buy-in to the process, and, ultimately, use of needs assessment results in planning and priority setting. Maximum points are given for involving all stakeholders in as many ways as possible. Question 12f asks if any other stakeholders made an important contribution to the needs assessment. Question 12g concludes this important series of questions by asking you to identify other groups that should be included more effectively in future needs assessment activities.

The rest of the questions in this section address how the needs assessment was conducted. **Question 13** is intended for a council or consortium that contracted some or all of its needs assessment to an individual consultant or organization.

It assesses the degree to which council or consortium members were involved in overseeing any consultants employed to help with the needs assessment. While consultants can bring valuable expertise to a needs assessment process, ownership and control of the process should remain with the council or consortium. Maximum points are given when the council or consortium remains extensively involved with consultants' work.

Question 14 is not scored but enables a council or consortium to highlight how it would use a consultant(s) better in the future.

Focus groups and key informant interviews are important and cost-effective ways of collecting qualitative information about service needs from the full range of stakeholders. In order to provide reliable information, all focus groups and interviews should be done using written guides. These guides clearly define the questions to be asked and may also define the order of questions. Also, interviews and focus groups should be implemented by interviewers/moderators who are carefully trained in the content and process of the interviews. Training can help minimize interviewer bias as well as help assure that consistent information (if desired) is collected. **Questions 15** and **16** award maximum points if guides are both developed and followed in the process of conducting interviews and focus groups, and if interviewers and moderators are trained to implement the guides.

Questions 17-25 relate specifically to surveys conducted with PLWH. Please refer to the discussion immediately preceding this section for an overview of the issues. Question 17 asks whether specific sub-populations were identified during the design of the survey(s). Question 18a explores the extent to which you considered specific strategies for reaching target sub-populations. Question 18b measures how successful you were in reaching these sub-populations. Maximum points are awarded for tackling the very difficult tasks involved in identifying

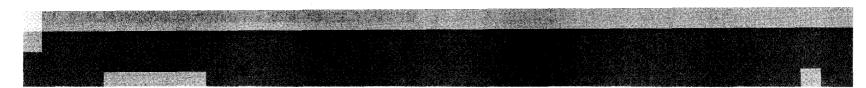
and reaching diverse and often hard-to-reach sub-populations. Specific populations (i.e., those currently priorities for DHS) are listed, but additional important sub-populations should be identified for each community. Questions 18c and 18d, two open-ended questions, enable you to highlight sub-populations not reached and barriers encountered. Sub-populations you did not consider, were unsuccessful reaching, or would like additional information on may be targeted in future surveys. List strategies in question 18d.

Questions 19-21 address how well you applied survey research principles and techniques to get survey responses that were as unbiased as possible. Question 19 asks about procedures to recruit people for participation in the survey. While true random selection of respondents may not be possible, every attempt should be made to avoid drawing respondents only from those who are most willing to answer the questions or are easiest to reach. For example, while you may choose to approach people at service delivery sites because you are trying to reach an infected population efficiently, you should approach people on a random basis. High points should be scored on this question if you defined and followed systematic procedures for selecting people to answer survey questions. Question 20 assesses the extent to which you were successful in getting people who were approached to complete the survey. Points are awarded on response rates achieved. Question 21 focuses on specific strategies you used to encourage high response rates and asks you to highlight particularly successful approaches.

In many surveys of PLWH, the people who respond to surveys may be different in important ways from the community. Sometimes this is due to intentional strategies to reach particular groups more than others, and other times it is due to logistical difficulties in reaching certain sub-populations. Whatever the reason, it is important to consider these differences in the analysis. In **questions 22** and **23**, points are awarded if a council or consortium examines the population that responded to the survey, compares it to the actual population in the community, and factors any differences into the analysis. While this can be a complicated undertaking, it is necessary to ensure that the results do not paint a distorted picture.

Question 24 asks whether survey instruments have been pretested. Pretests reveal important information about how long it takes to complete the instrument, which questions are confusing, and whether the flow of questions is clear. When instruments have been translated, it is particularly important to pretest the translated version within the same language-speaking group that will complete it. The pretest need not be complicated, especially if the instrument has been used in other settings. For example, an instrument could be tried in a focus group with feedback provided at the time.

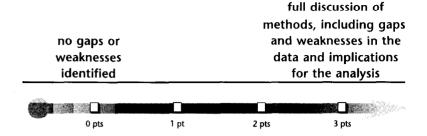
Question 25, the final question in the section, is a general one about the usefulness of the questions in the survey. It is intended to reinforce the importance of asking questions that lead to useful information for planning and prioritizing service needs of PLWH. It also will help you think about which questions should be asked in future survey efforts.



OUTCOMES OF THE NEEDS ASSESSMENT

C. ANALYSIS AND RESULTS How adequately did the data analysis answer the study questions or objectives defined for the needs assessment? all questions no questions or objectives or objectives answered/met answered/met 0 pts 1 pt 2 pts 3 pts How well did the data analysis integrate qualitative and quantitative data in answering questions? the analysis fully integrated qualitative the analysis did and quantitative data in not attempt to link answering all questions qualitative and quantitative data (as appropriate) 0 pts 1 pt 2 pts 3 pts Were report(s) of the data analysis easy to understand? reports were reports were very difficult to very easy to understand understand 0 pts 1 pt 2 pts 3 pts

Did the report(s) identify gaps or weaknesses in the data or study design?



Did the results of the needs assessment address general needs for each sub-population of interest?

Needs assessments should consider needs across the full continuum of care for all key sub-populations of PLWH. Defining primary care needs is a particular priority for CARE Act-funded planning councils and consortia. Refer to the Attachment at the end of this module for a discussion of the continuum of care and a definition of primary care. Or refer to the Continuum of Care module. The following chart is intended to help answer questions 30a-c. \Rightarrow



Question 30	Addressed Service Needs				
		ADDRESSED SE IN GENERAL SUB-POPU	FOR EACH	ADDRESSED PR NEEDS FO SUB-POPU	R EACH
Sub-population		No No	Yes (III)	Harrista No Large La	
Women					
Pregnant women					
White men who have se	x with men				
Men of color who have	sex with men				
Injecting drug users					
Other					
Other					

30a	To what extent did the needs assessment address service needs for all sub-populations of interest?			general needs fully addressed for all sub-populations	
		0 pts	- 1 pt	2 pts	3 pts
3 0b	To what extent did the needs assessment address primary care needs for all sub-populations of interest?	primary care needs not addressed for any sub-populations		primary care needs fully addressed for all sub-populations	
30c	List sub-populations whose general and/or primary care needs have not been adequately assessed and should be the focus of future needs assessments.	0 pts	1 pt	2 pts	3 pts
	Sub-population(s)	Strategy(ies)			

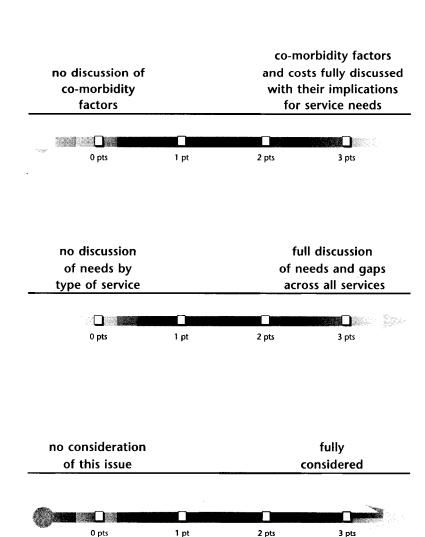
Did the needs assessment analyze co-morbidity factors that may indicate severe need and affect HIV service needs and/or costs (e.g., homelessness, substance abuse, TB, STDs, and severe mental illness)?

Did the needs assessment quantify needs and gaps across all services included in the HIV continuum of care for each sub-population? (Refer to ATTACHMENT,

page 70 and Continuum of Care module.)

To what extent did the needs assessment examine the following barriers to PLWH receiving services?

33 Financial (e.g., no insurance coverage, inability to pay)

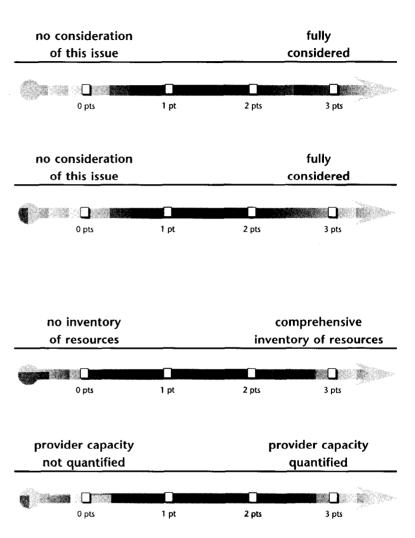


Logistical (e.g., travel distance or time, hours of operation, waiting lists for appointments, accessibility to transportation, handicapped accessibility, child care)

Cultural (e.g., language, provider attitudes, appropriate treatment)

Did the needs assessment identify service resources available across the full continuum of care needed by PLWH in the community? (Refer to ATTACHMENT, page 70 and Continuum of Care module.)

Did the needs assessment quantify the capacity of providers to render services to PLWH?





36	What populations, services, or barriers were not adequately addressed in the needs assessment?				
37	Did the needs assessment include an analysis of trends in epidemiological data on HIV and AIDS since the outset of the epidemic and over the last two years?	no discussion of AIDS epidemiology		complete discussion of AIDS epidemiology since the outset of the epidemic and over the last two years	
		0 pts	1 pt	2 pts	3 pts
38	Did the needs assessment use the state's surveillance data to analyze incidence, prevalence, and trends of AIDS?	surveillance data not used		used incider	reillance data d to describe nce, prevalence, rends in detail

0 pts 1 pt 2 pts 3 pts

38a Did the needs assessment use CDC HIV prevalence estimates?

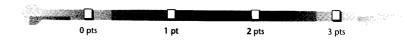
CDC HIV prevalence estimates not used

CDC estimates used for assessing HIV prevalence



To what extent did the assessment address the evolution of needs over time from the outset of the epidemic to the present, emphasizing the last two years?

no discussion of evolution of needs over time full discussion of trends based on data



To what extent did the assessment project needs three to five years into the future?

no future projections

detailed projections for next 3-5 years





To what extent did the needs assessment report address the issues listed below? (Use the box to help answer this question.)

no report		all issues		
developed		fully addressed		
			 	
0 pts	1 pt	2 pts	3 pts	

Question 41 Contents of Needs Assessment Report			
REPORT INCLUDI	ED	NO	YES
Why assessment was cor	nducted		
Goals/objectives/research	n questions		
Methods			
Results/findings (both ov	verall and for sub-populations)		
Implications and recomr	nendations for action		
Need for further study			

SUMMARY: ANALYSIS AND RESULTS

SCORING		STRENGTHS AND WEAKNESSES	
To scor	re, follow these steps:	What aspects of the analysis worked well and should be retained	
STEP 1	Add up the points for questions 26 through 41 and put that amount in the TOTAL POINTS box.		
STEP 2	Add up the number of scored questions answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.		
STEP 3	Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.	What should be improved?	
STEP 4	Record your final score in the SCORE box.*		
SCOR	TOTAL POINTS divided by		
	TOTAL NUMBER OF SCORED QUESTIONS ANSWERED	ACTION STEPS	
	equals SCORE	Based on your responses to questions 26 through 41, list the key areas where action is needed. Action steps may address areas of strength that the planning council or consortium wants to retain in future needs assessments, aspects of the	



needs assessments that should be modified, and/or additions

to improve future assessments. ->

*If your score equals more than 3, double-check your addition of points and counting of subquestions answered.

To what extent did the needs assessment report address the issues listed below? (Use the box to help answer this question.)

no report			all issues	
developed		fully addressed		
			· · · · · · · · · · · · · · · · · · ·	
0 pts	1 pt	2 pts	3 pts	

Question 41 Contents of Needs Assessment Report			
REPORT INCLUDI	ED	NO	YES
Why assessment was co	nducted		
Goals/objectives/research	n questions		
Methods			
Results/findings (both overall and for sub-populations)			
Implications and recommendations for action			
Need for further study			

SUMMARY: ANALYSIS AND RESULTS

To score, follow these steps:		STRENGTHS AND WEAKNESSES	
		What aspects of the analysis worked well and should be retained?	
STEP 1	Add up the points for questions 26 through 41 and put that amount in the TOTAL POINTS box.		
STEP 2	Add up the number of scored questions answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.		
STEP 3	Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED	What should be improved?	
STEP 4	Record your final score in the SCORE box.*		
SCOR	TOTAL POINTS divided by		
	TOTAL NUMBER OF SCORED QUESTIONS ANSWERED	ACTION STEPS	
	equals	Based on your responses to questions 26 through 41, list the key areas where action is needed. Action steps may address	
	SCORE	areas of strength that the planning council or consortium wants to retain in future needs assessments, aspects of the	

*If your score equals more than 3, double-check your addition of points and counting of subquestions answered.

needs assessments that should be modified, and/or additions

to improve future assessments. ->



ACTION STEPS FOR QUESTIONS 26-41

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:

ANALYSIS AND RESULTS: DISCUSSION OF SCORING AND QUESTIONS 26-41

Following is a discussion of questions 26-41. This section asks about what results were obtained from the needs assessment, and how the results were analyzed and reported. It explores the degree to which results were produced for each of the various components of a comprehensive needs assessment: an epidemiological profile, an assessment of service needs for each key sub-population, an inventory of service resources, an assessment of provider capacity and access barriers, and a quantification of gaps in services. For a planning council or consortium that has completed only some components of a needs assessment, not all questions can be answered. However, the questions may be helpful in identifying areas of focus for future needs assessment activities.

Beginning the section, question 26 provides an overview of how well the analysis addressed the study questions. A low score on this question should lead to specific objectives in the action plan to improve the analysis in future assessments.

Question 27 gives high points if the analysis integrates quantitative and qualitative data. Question 28 emphasizes the importance of developing reports that are clear. This is an important step in ensuring that reports can be used in the planning and priority-setting processes. Question 29 awards high points if the analysis report(s) discusses gaps and weaknesses in the needs assessment. This information helps people interpret the results of the report(s); it is not a judgment of the assessment.

Question 30 asks whether the results of the needs assessment looked at needs across the continuum of care for key subpopulations. The sub-populations considered high priority by DHS are listed, but each community should augment this list with other sub-populations important in their area. Question 30a asks for an overall assessment of whether service needs were considered for all sub-populations identified as a priority in the service area. High points should be awarded if general needs were identified for sub-populations. Question 30b asks specifically about the assessment of need for primary care services, a priority of the CARE Act. Question 30c allows you to identify sub-populations and specific service needs which should be the focus of future needs assessments.

Benchmark: A needs assessment should address all population groups affected by HIV. Key groups must be addressed, including women (pregnant women too), adolescents, white men who have sex with men, men of color who have sex with men, and injecting drug users. Other groups should be considered if they are affected differentially in an area.

In addition to looking at needs for specific sub-populations, needs assessments should look at co-morbidity factors which may affect HIV service needs. **Question 31** assesses the extent to which this was done. It is often difficult for a council or consortium to get specific information on co-morbidity factors and their implications for service. High points should be given



if both qualitative and quantitative information on co-morbidity factors was obtained and included in analyses of results.

B B Alexander

Benchmark: Planning councils should demonstrate severe need, based on the presence of co-morbidity factors, such as TB, STDs, substance abuse, and severe mental illness, as well as on homelessness and/or new or growing sub-populations with HIV disease, using quantitative data where available. Consortia should also examine the effect of co-morbidity factors on need.

Question 32 asks whether the needs assessment has quantified gaps in service. This is the end result of a comprehensive needs assessment, and councils or consortia that score high on this item should be able to focus on fine-tuning and updating their needs assessment.

Questions 33a-c address barriers to service, although they barely scratch the surface of this important issue. PLWH may face many barriers to receiving services, and it is critical to isolate and identify specific barriers in order to facilitate access best. High scores should be given if the needs assessment results discussed specific barriers in each category listed (financial, logistical, cultural) or other categories of the council or consortium's choosing. The questions are not intended to provide a comprehensive list of possible barriers but should lead a council or consortium to identify specific barriers in its community that should be addressed in the needs assessment.

Question 34 asks whether a resource inventory has been

completed as part of the needs assessment. A high score should be given if the inventory covers the full range of services identified in the community's continuum of care.

Question 35 builds on this and asks whether the capacity of providers to render services has been quantified.

Question 36 provides an opportunity to summarize the answers for **questions 30-35** and highlights the populations, services, or barriers that have not been adequately addressed. This open-ended question should lead directly into the action plan for this section.

An analysis of epidemiological data, both to define the current prevalence of HIV and AIDS among specific sub-populations in a community and to discern trends in the epidemic, is an essential part of any needs assessment. **Question 37** asks about use of epidemiological data in general. **Questions 38** and **38a** ask specifically about AIDS surveillance data compiled by the state health department and about HIV prevalence estimates developed by CDC.

Questions 39 and 40, the next two questions in this section, address the extent to which the needs assessment discusses the evolution of the service needs and projects those needs three to five years into the future. Looking backward at trends helps to understand how the epidemic is evolving. Looking forward is necessary to plan effectively to meet service needs. In places where the epidemic is evolving quickly, it may be difficult to project some trends more than one to two years into the future. Further, rapid treatment advances make predicting future service needs guesswork in many instances. Still, projecting service needs beyond the present is an important basis for planning. High scores should be given for discussing trends and projecting future needs.

Question 41, the final question in this section, highlights issues that should be addressed in a publicly available report on the needs assessment. While your headings may be different, it is important that the report describe why the needs assessment was conducted; its goals, objectives, and research questions; the methods that were used to conduct the assessment (including a description of any weaknesses or gaps in the methods); results and findings, both overall and for each category of stakeholder and each sub-population within categories; implications of the findings and recommendations for action; and, areas for further study. Award maximum points if these issues were covered comprehensively in the report, and zero points if no report was developed.



D. DISSEMINATION AND USE OF THE NEEDS ASSESSMENT



Were results of the needs assessment distributed to all key stakeholder groups? (Refer to Figure 1 for list of stakeholders.)

needs assessment
results were
not distributed

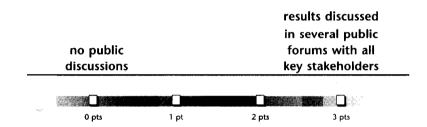
opts

1 pt

2 pts

3 pts

Were discussions of results held in public forums?



To what extent was the needs assessment used in defining or refining the continuum of care for people with HIV disease in the area covered? (Refer to ATTACHMENT, page 70 and Continuum of Care module.)

not a factor in defining the continuum of care

assessment used directly and substantially in defining or refining the continuum of care



To what extent was the needs assessment used for developing or refining a comprehensive plan for services? (Refer to Comprehensive HIV Services Planning module.)

not a factor in developing a comprehensive plan assessment used directly and substantially in developing or refining a comprehensive plan

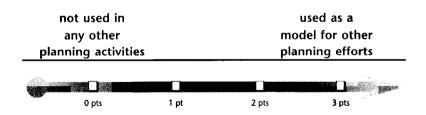




To what extent were the needs assessment results used in CARE Act-related priority setting and resource allocation? (Refer to Priority Setting and Resource Allocation module.)

priorities drawn directly from the not used **Priority Setting** at all needs assessment 3 pts 0 pts 1 pt 2 pts resource allocation directly related to not used Resource Allocation at all needs assessment 0 pts 1 pt 2 pts 3 pts

To what extent was the needs assessment used in other planning activities?



SUMMARY: DISSEMINATION AND USE

SCORING		STRENGTHS AND WEAKNESSES	
To score	e, follow these steps:	What aspects of disseminating and using the needs assessment	
STEP 1	Add up the points for questions 42 through 47 and put that amount in the TOTAL POINTS box.	worked well and should be retained?	
STEP 2	Add up the number of scored questions answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.		
STEP 3	Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.	What should be improved?	
STEP 4	Record your final score in the SCORE box.*		
Scoo			
SCUR	TOTAL POINTS		
	divided by		
	TOTAL NUMBER OF SCORED QUESTIONS ANSWERED	ACTION STEPS	
	equals		
	SCORE	Based on your responses to questions 42 through 47, list the key areas where action is needed in disseminating and using needs assessment. Action steps may address areas of strength that the	



planning council or consortium wants to retain in future needs

assessments, aspects of the needs assessments that should be modified, and/or additions to improve future assessments.

^{*}If your score equals more than 3, double-check your addition of points and counting of subquestions answered.

DISSEMINATION AND USE: DISCUSSION OF SCORING AND QUESTIONS 42-47

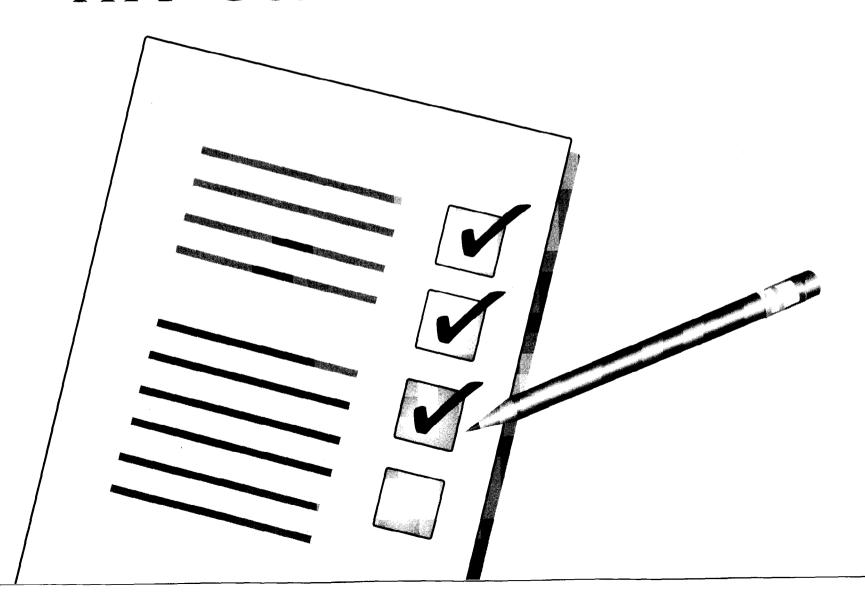
The following discussion covers questions 42-47. The section is brief but asks critical questions about how the needs assessment was distributed, and, even more importantly, how it was used to make decisions.

Question 42 asks whether results were widely distributed to key stakeholders. This is important for many reasons: to recognize people for their participation and to encourage involvement in future assessments; to encourage broad-based buy-in; and to enable results to be used in planning throughout the community. High points should be given if the results were widely disseminated.

Question 43 asks whether results were discussed in a public forum, encouraging greater buy-in and wider use of assessment results. Also, the discussion often leads to constructive ideas for future assessment activities. Needs assessments are not ends in themselves. They are worth the time and expense only if they help ensure that accessible and appropriate services are made available to people living with HIV disease.

The final series of questions in this module asks about how the results of the needs assessment were used in defining or refining the continuum of care for PLWH (question 44); developing the comprehensive plan (question 45); setting priorities and allocating resources (question 46); and other planning activities (question 47). High points are given when the needs assessment is used to make decisions in each of these areas.

ATTACHMENT: HIV CONTINUUM OF CARE



HIV CONTINUUM OF CARE

Continuum of care is a term encompassing the comprehensive range of services required by individuals or families with HIV infection in order to meet their health care and psychosocial service needs throughout the course of their illness. The concept of a continuum suggests that services must be organized to respond to the individual or family's changing needs in a holistic, coordinated, timely, and uninterrupted manner, reducing fragmentation of care. The continuum must also include strategies for linking services, so that from the perspective of people living with HIV disease, there exists a "seamless" service delivery system.

The continuum of care must be defined by and for each community. The defined continuum of care should be the ideal set of services and set of mechanisms for linking services that would be available to PLWH if the community had unlimited resources to allocate to HIV care. From this "wish list," the community should define its "core" continuum of care. The core continuum of care is the set of services and mechanisms to link services that a planning council or consortium has decided should be available to PLWH in their community. Neither the ideal continuum of care nor the core continuum of care is defined only by the resources directly available to the planning council or consortium. The planning council or consortium's funded continuum of care should represent a subset of the core continuum of care.

The following categories of services should be considered for inclusion in the continuum of care:

- 1. Ambulatory/Outpatient Medical Care: Provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient, community-based, and/or office setting. This includes diagnostic testing, early intervention and risk assessment, preventative care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, care of minor injuries, education and counseling on health and nutritional issues, minor surgery and assisting at surgery, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care.
- 2. Case Management: A range of client-centered services that link clients with health care, psychosocial and other services to ensure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, and ongoing assessment of the client's and other family members' needs and personal support systems. Key activities include initial comprehensive assessment of the client's needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic reevaluation and revision of the plan as necessary over the life of the client. May include client specific advocacy and/or review of utilization of services.
- 3. **Dental Care:** Diagnostic, prophylactic, and therapeutic services rendered by dentists, dental hygienists, and similar professional practitioners.

- 4. **Emergency Services:** Medical care for acute conditions requiring immediate care. Usually provided in a hospital emergency room.
- 5. Home Health Care: Therapeutic, nursing, supportive, and/or compensatory health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professionals. Component services are defined separately below:
 - a. **Para-Professional Care:** homemaker, home health aide, and personal/attendant care
 - b. **Professional Care**: routine and skilled nursing, rehabilitation, and mental health
 - c. **Specialized Care**: intravenous and aerosolized medication treatments, diagnostic testing, parenteral feedings, and other high-technology services
 - d. Durable Medical Equipment: prosthetics, devices, and equipment used by clients in home/residential setting, e.g., wheelchairs, inhalation therapy equipment, or hospital beds.

6. Hospice Care:

a. Home-Based Hospice Care: Nursing care, counseling, physician services, and palliative therapeutics provided by a hospice program to patients in the terminal stages of illness in their home setting.

- b. Residential Hospice Care: Room, board, nursing care, counseling, physician services, and palliative therapeutics provided to patients in the terminal stages of illness in a residential setting, including a non-acute care section of a hospital that has been designated and staffed to provide hospice services for terminal patients.
- 7. Inpatient Services: Care for acute episodes of illness in a secondary or tertiary care facility. Inpatient services include primary and specialty physicians, nursing care, medications, treatments, and ancillary services such as laboratory and x-ray while in the hospital. Inpatient services also include discharge planning and case management to facilitate access to other services. Title I grantees may spend up to ten percent of the total award for such costs upon determination by the HIV Health Services Planning Council that a shortage of inpatient personnel exists. ("...case management services that prevent unnecessary hospitalization or that expedite discharge as medically appropriate...." Sec. 2604, (a) (1) (B))
- 8. Long-Term Care: Maintenance or rehabilitative care in a residential facility in which nursing and medical care are essential aspects of the services.
- 9. Medications and Therapeutics: Provision of prescription drugs and therapies to prolong life or prevent the deterioration of health, including measures for the prevention and treatment of opportunistic infections, and the prevention of perinatal transmission of HIV. This may be done as part of a locally or state administered drug assistance program.



- 10. Mental Health Therapy/Counseling: Psychological and psychiatric treatment and counseling services, including individual and group counseling provided by a mental health professional licensed or authorized within the state, psychiatrists, psychologists, clinical nurse specialists, social workers, and counselors.
- Nutritional Services: Provision of education, counseling, and/or direct therapeutic nutritional/supplemental food services.
- 12. **Rehabilitation Care:** Services provided by a licensed or authorized professional in accordance with an individualized plan of care which is intended to improve or maintain a client's quality of life and optimal capacity for self-care. This definition includes physical therapy, speech pathology, and low-vision training services.
- 13. **Substance Abuse Treatment/Counseling:** Provision of treatment and/or counseling to address substance abuse (including alcohol) problems in an outpatient or residential health service setting.

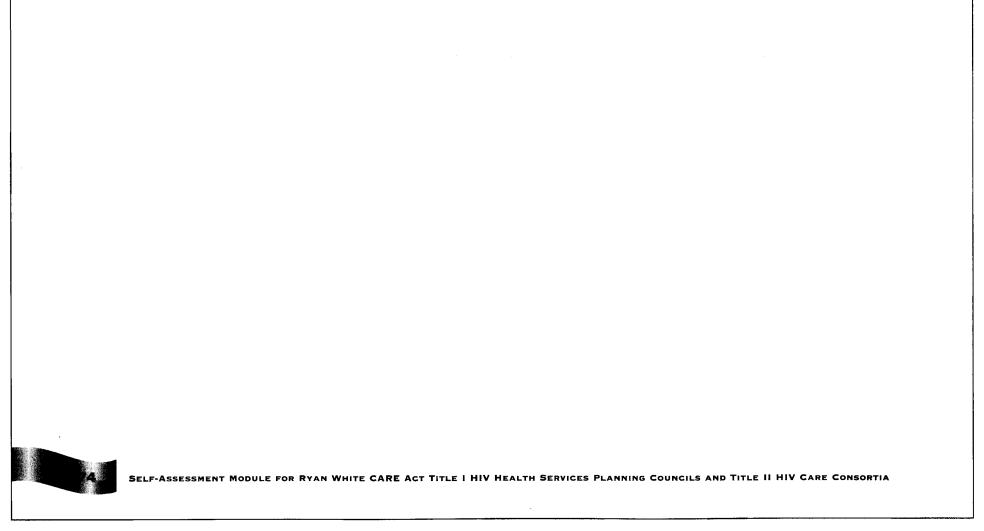
14. Support Services:

- a. Adoption/Foster Care Assistance: Assistance in placing children younger than 20 years in temporary (foster care) or permanent (adoption) homes because their parents have died or are unable to care for them.
- b. **Buddy/Companion Services:** Activities provided by volunteers/peers to assist the client performing household or personal tasks. Also, mental and social support to combat loneliness and isolation.

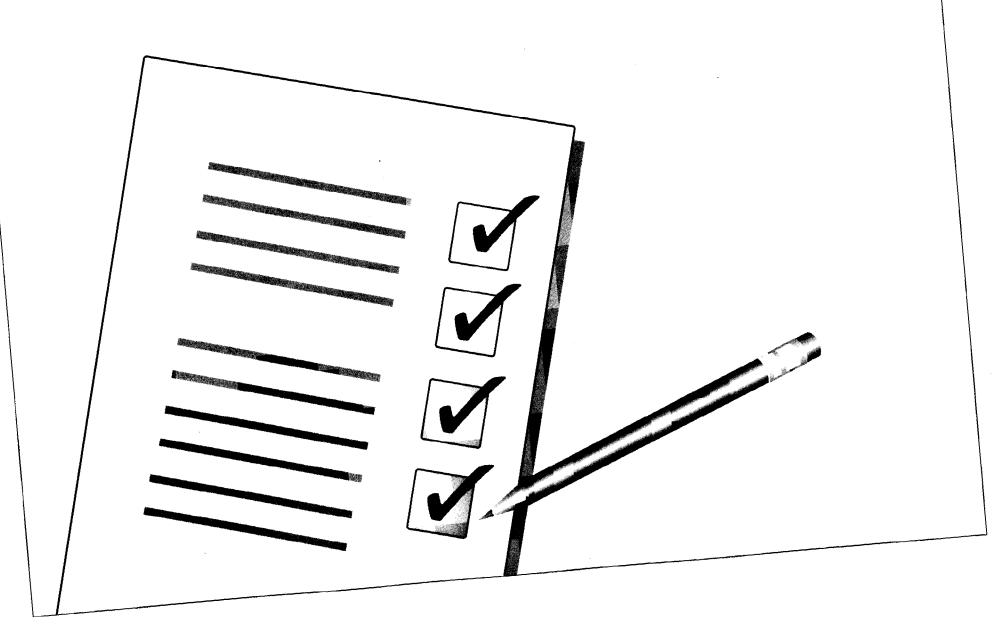
- c. Client Advocacy: Assessment of individual need, provision of advice and assistance obtaining medical, social, community, legal, financial, and other needed services. Advocacy does not involve coordination and follow-up on medical treatments.
- d. Counseling (Other): Individual and/or group counseling services other than mental health counseling provided to clients, family and/or friends by non-licensed counselors. May include psychosocial providers, peer counseling/support group services, benefits counseling, caregiver support/bereavement counseling, drop-in counseling, benefits counseling, and/or nutritional services.
- e. Day or Respite Care: Home- or community-based medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of client or client's child.
- f. Direct Emergency Financial Assistance: Provision of short-term payments to agencies, or establishment of voucher programs, to assist with emergency expenses related to food, housing, rent, utilities, medications, or other critical needs.
- g. Food Bank/Home-Delivered Meals: Provision of actual food or meals, not finances to purchase food, meals, or nutritional services.

- h. Housing Assistance/Housing-Related Services:
 This includes assistance in locating and obtaining suitable, ongoing, or transitional shelter; costs associated with finding a residence and/or subsidized rent; and the provision of housing assistance in a group home setting.
- Transportation: Conveyance services provided to a client to gain access to health care or psychosocial support services. May be provided routinely or on an emergency basis.
- j. Other Support Services: Direct support services not listed above, such as translation/interpretation services, outreach, alternative therapies prescribed by a licensed provider (e.g., acupuncture for pain management or as part of a substance abuse treatment plan).





RESOURCES



Below is a list of legislative, HRSA documents, articles, and books related to this topic.

LEGISLATION

 CARE Act of 1990 as amended by the Ryan White CARE Act Amendments of 1996.

HRSA DOCUMENTS

- Activities of Ryan White CARE Consortia, FY 1993, Conviser, R. October, 1994.
- First Year Experience of Title I Eligible Metropolitan Areas with Standard Protocol for Baseline Data Collection, Division of HIV Services.
- FY 1997 Title I Formula Grant Application Guidance.
- FY 1997 Title I Supplemental Grant Application Guidance.
- FY 1997 Title II Application Guidance.
- Letter to Title I Colleagues (March 6, 1996) with enclosure entitled "Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas."
- Needs Assessment: Technical Assistance Conference Call, Report by MOSAICA, The Center for Nonprofit Development and Pluralism, Washington, D.C., June, 1996.

ABSTRACTS, ARTICLES, AND REPORTS

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- Maine Community AIDS Partnership. Maine: A Report on HIV/AIDS Needs. 1994.
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 A Community Based Needs Assessment of People Living With and Affected by HIV/AIDS. 1994.
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- Mangione, T. Mail Surveys: Improving the Quality.
 Thousand Oaks, CA: Sage, 1995.
- Sudman, S., and Bradbum, N.M. Asking Questions: A Practical Guide to Questionnaire Design.
 San Francisco: Jossey-Bass Publishers, 1992.

